

Ten topics in ethical research

From *Ethics, social research and consulting with children and young people*, Priscilla Alderson and Virginia Morrow, Barnardo's 2004, updated 2011 *The Ethics of research with Children and Young People: A Practical Handbook*. Sage.

Here is a summary of the practical questions raised through the ten main chapters of the book, with a sample information leaflet..

1. The purpose of the research

- What is the research for?
 - to learn more about children's and young people's views, experiences or abilities?
 - to develop or evaluate a service or product?
 - some other positive purpose?
- Whose interests is the research designed to serve?
- If the research findings are meant to benefit certain children, who are they and how might they benefit?
- What questions is the research intended to answer?
- Why are the questions worth investigating?
- Has earlier research answered these questions?
- If so, why are the questions being re-examined?
- How are the chosen methods best suited to the research purpose?

Summary of the main questions in chapter 2

2. Costs and hoped-for benefits

- What contributions are children asked to make to the research? such as activities or responses to be tested, observed or recorded?
- Might there be risks or costs?
 - time, inconvenience, embarrassment, intrusion of privacy, sense of failure or coercion, fear of admitting anxiety?
- Might there be benefits for children who take part in the research?
 - satisfaction, increased confidence or knowledge, time to talk to an attentive listener?
- Are there risks and costs if the research is not carried out?
- How can the researchers promote possible benefits of their work, and prevent or reduce any risks?
- How will they respond to children who wish to refuse or withdraw, or who become distressed?
- Are the research methods being tested with a pilot group?

3. Privacy and confidentiality

- How will the names of children be obtained, and will they be told about the source?
- Will children and parents be able to opt in to the research (such as by returning a card if they wish to volunteer)?
 - Opt out methods (such as asking people to 'phone to cancel a visit) can be intrusive.
- Is it reasonable to send reminders, or can this seem coercive?
- Will research directly with individuals be conducted in a quiet, private place?
- Can parents be present or absent as the child prefers?

- In rare cases, if researchers think that they must report a child's confidences, such as when they think someone is in danger, will they try to discuss this first with the child?
- Do they warn all children that this might happen?
- Will personal names be changed in records and in reports to hide the child's identity?
- What should researchers do if children prefer to be named in reports?
- Will the research records, notes, tapes, films or videos, be kept in lockable storage space?
- Who will have access to these records, and be able to identify the children?
 - Using post codes instead of names does not protect anonymity.
- When significant extracts from interviews are quoted in reports, should researchers first check the quotation and commentary with the child or parent concerned?
- What should researchers do if respondents want the reports to be altered?
- Before researchers spend time alone with children, are their police records be checked?
- Should research records be destroyed when a project is completed, as market and medical researchers are required to do?
- Is it acceptable to re-contact the same children and ask them to take part in another project?

4. Selection, inclusion and exclusion

- Why have the children concerned been selected to take part in the research?
 - Do any of them belong to disadvantaged groups?
 - If so, has allowance been made for any extra problems or anxieties they may have?
 - Have some children been excluded because, for example, they have speech or learning difficulties (Lewis 2002)?
 - Can the exclusion be justified?
 - If the research is about children, is it acceptable only to include adult subjects?
 - Are the research findings intended to be representative or typical of a certain group of children?
- If so, have the children been sufficiently well selected to support these claims?
- Do the research design and the planned numbers of children allow for refusals and withdrawals?
 - If too many drop out, the research is wasted and unethical.

5. Funding

- Should the research funds be raised only from agencies that avoid activities that can harm children?
- Does the funding allow for time and resources to enable researchers
 - to liaise adequately with the children?
 - to collect, collate and analyse the data efficiently and accurately?
- Are the children's and parent's or carers' expenses repaid?
- Should children be paid or given some reward after helping with research?

6. Review and revision of the research aims and methods

- Have children or their carers helped to plan or comment on the research?

- Has a committee, a small group or an individual reviewed the protocol specifically for its ethical aspects and approach to children?
- Is the design in any way unhelpful or unkind to children?
 - Is there scope for taking account of comments and improving the research design?
 - Are the researchers accountable to anyone, to justify their work?
 - What are the agreed method of dealing with complaints?

7. Information

- Are the children and adults concerned given details about the purpose and nature of the research, the methods and timing, and the possible benefits, harms and outcomes?
- If the research is about testing two or more services or products are these explained as clearly and fully as possible?
- Are the research concepts, such as 'consent', explained clearly?
- Are children given a clearly-written sheet or leaflet to keep, in their first language?
- Does a researcher also explain the project and encourage them to ask questions, working with an interpreter if necessary?
- Does the leaflet give the names and address of the research team?
- How can children contact a researcher if they wish to comment, question or complain?
- If children are not informed, how is this justified?

8. Consent

- As soon as they are old enough to understand, are children told that they can consent or refuse to take part in the research?
- Do they know that they can ask questions, perhaps talk to other people, and ask for time before they decide whether to consent?
- Do they know that if they refuse or withdraw from the research this will not be held against them in any way?
- How do the researchers help the children to know these things, and not to feel under pressure to give consent?
- How do they respect children who are too shy or upset to express their views freely?
- Are parents or guardians asked to give consent?
- What should researchers do if a child is keen to volunteer but the parents refuse?
- Is the consent written, oral or implied?
- If consent is given informally, how do the researchers ensure that each child's views are expressed and respected?
- If children are not asked for their consent, how is this justified?

9. Dissemination

- Does the research design allow enough time to report and publicise the research?
- Do the reports show the balance and range of evidence?
- Will the children and adults involved be sent short reports of the main findings?
- Will the research be reported in popular as well as academic and practitioner journals, so that the knowledge gained is shared more fairly through society?

- Can conferences or media reports also be arranged to increase public information, and so to encourage the public to believe that it is worthwhile to support research?
- Will the researchers meet practitioners to talk with them about practical ways of using the research findings?

10. Impact on children

- Besides the effects of the research on the children involved, how might the conclusions affect the larger groups of children?
- What models of childhood are assumed in the research?
 - Children as weak, vulnerable and dependent on adults? As immature, irrational and unreliable? As capable of being mature moral agents? As consumers?
- How do these models affect the methods of collecting and analysing data?
- Is the research reflexive, in that researchers critically discuss their own prejudices?
- Do they try to draw conclusions from the evidence, or use the data to support their views?
- Do they aim to use positive images in reports, and avoid stigmatising, discriminatory terms?
- Do they try to listen to children and to report them on children's own terms though aware that children can only speak in public through channels designed by adults?
- Do they try to balance impartial research with respect for children's worth and dignity?

An example of an information leaflet for children and parents posted to them at home, by hospital staff

Living with diabetes
A research project
August - December 2003

This leaflet is for children aged 3-12 years
and their parents

Please will you help us with our research?

*This leaflet gives some details about the project.
We have set out the questions you might want to ask,
with our answers, so you can talk about them together
before you decide if you would like to take part.*

Please contact us, Katy or Priscilla,
if you want more details and/or
if you would like to join the project.

Katy Sutcliffe (phone and email)
Priscilla Alderson (phone and email)
(address)

Why is the research being done?

As you know, the way you care for yourself is vital to help you to keep healthy. But, so far, researchers have not asked children much about how they share in their own diabetes care.

We plan to listen to boys and girls, parents/carers, and health staff, and write reports about their views.

The aim is to help families and health care staff know more about the kinds of daily diabetes care that children and parents find work well.

What questions will the project ask?

- * How do girls and boys with diabetes share in their daily health care, such as deciding what to eat and when?
- * When are they old enough to do blood tests?
- * Do you have any problems with diabetes? And, if so, how do you and your parents try to solve these?
- * Do you remember when you first knew you had diabetes? Have there been any changes in your care since then? Would you like to make other changes?
- * What do you find works well?
- * How would you advise someone who has diabetes?

Who will be in the project?

Ten boys and girls at X ---- Hospital
and ten boys and girls at Y ---- Hospital, and their parents.

The age groups are 3-6 and 10-12 years.

Dr B----- has chosen the children at your hospital to be asked to take part. He has not told us your names.

Do I have to take part?

You decide if you want to take part or not.

Even if you say `yes', you can drop out at any time.

And you can tell us if you want to stop, or have a break.

If you don't want to answer some questions, just say `pass'. You do not have to tell us anything unless you want to. And you don't have to give us a reason if you say `no' or `stop'. Whether you help us or not, you will still go on having just the same care at your hospital.

What will happen to me if I take part?

If you agree, one of us will meet you at your home, or at the clinic, to talk to you, and your mother or father. We would like to tape-record you. You might play some games and talk with us for between 15 to 60 minutes. We will not look for right or wrong answers, it is your own views that matter. Later, we'll ask you to test a question booklet we will be writing for other children.

Could there be any problems for me if I take part?

We hope you will enjoy talking to us. A few people get upset when talking about their lives, and if they want to stop, we stop. We can put them in touch with someone to help them, if they wish. If you have any complaints about the project, please tell us, or Dr B-----.

Will doing the research help me?

We hope you will like helping us. But our main aim is to write reports that will help very many families in the future. Maybe you too will find the reports useful.

**Who will know if I am in the research,
or what I have talked about?**

Dr B----- will know if you are in the project, but we will not tell him or anyone else what you tell us.

The only time we might have to break this promise is if we think you or someone else might be at risk of being hurt. If so, we will talk to you first about the best thing to do.

We will keep our tapes and notes about you in a safe lockable place, and delete named details about you after the project.

When we write reports about your views, we will change your name, so no one will know you said that.

Will I know about the research results?

We will send you a short report in Spring 2004, and longer reports too, if you want to see them.

The project is funded by a Social Science Research Unit grant.

It was approved by X----- Hospital Research Ethics Committee, project no. 405, and by Dr B -----.

The researchers, Priscilla and Katy, do research and write reports and books about children's and parents' views on health care and education.

If you take part, please keep this leaflet with the copy of your consent form.

June 2003, leaflet version 1.

Thank you for reading this leaflet.